

You Are the One...

By Susan Addison

You are the one...
who dreams of a world where all
children are fed, happy, healthy,
cherished, and included

You are the one...
Who sees no end to the stream of
families and children in need

You are the one...
Who locks the building up at night after
others have gone home

You are the one...
Offering tissues to a grieving parent

You are the one...
Mourning the loss of yet another
beloved child

You are the one...
Seeking resources that often are not
there

You are the one...
Driving tirelessly in search of that hidden
house...because there is a child inside

You are the one...
Whose knock is sometimes refused

You are the one...
Returning another day, no matter how
far

You are the one...
Dreaming of children rising from
wheelchairs to run and play

You are the one...
Listening to the hopes and dreams of
those with babies in distress

Who are you?

You are the early intervention service
coordinator
You make a real difference

And still...

Though you are the one bringing hope
to children and families,
you are not the one upon which a
cherished child depends for lifelong
support

Only the family shoulders this
responsibility across the lifespan of their
child

You are the one...
Privileged to partner with families for a
brief time on their journey of hope





ABC's of Special Needs

What if this happened to you?

The purpose of this activity is to help service coordinators increase their understanding of the demands families of children with special needs experience on a regular basis. Becoming sensitive to the day-to-day realities families face will encourage understanding and empathy, and reinforce the importance of family-centered care.

- A. You have tried for two years to have a family and have experienced two miscarriages in the process. You just celebrated the birth of your first child only to be told that there is a problem. Your child has been diagnosed with a cranial facial anomaly and a heart defect. Describe your feelings. Describe how you will share this news with your elderly parents.
- B. You ran into the grocery store to grab what you need for dinner. You have just picked up your toddler who has autism from his child care program, and the change in routine has upset him. Inside the store, the noise and visual stimulation prove too much for him. He falls to the floor and begins to cry loudly. A woman walking by comments that her child would never behave like that in public. Describe your feelings. What would you do?
- C. Your early intervention team has recommended physical therapy for your daughter. You believe this would make a significant difference in her progress. However, your spouse is very much against this recommendation and feels your daughter will outgrow this concern. Describe your feelings. How would you react?
- D. You are a parent who just received a second overdue notice from your child's assistive technology provider. You have discussed this purchase with your insurance provider for the past month with no resolution in sight. Describe your feelings. What would you do?
- E. Your IFSP team recommends a full child care program for your son. You have stopped working in order to stay home with him. You prefer that your son's needs be addressed in the home, but feel intimidated by the team's expertise. Describe your feelings. What would you do?

- F. You live in a rural area, and your phone service has been discontinued because you do not have the money to pay the bill. Your daughter is medically fragile, and you need to be able to speak with her physicians and to call for help if needed. What would you do? How do you feel about asking for help?
- G. It is your child's second birthday. She is not sitting up and is unable to be fed by mouth. A guest finds you crying in the kitchen as you prepare to bring in the cake. Explain how you feel.
- H. You and three of your friends from high school all had babies born within six months of each other. You learn that they planned an outing to the park and did not include you and your child who uses a wheelchair. Describe your feelings. What would you do?
- I. Your service coordinator left a huge packet of information for you to read. Because your child has had multiple doctor's appointments and therapy visits, you haven't had time to look at the information. Tomorrow four people are coming to your house to write some kind of plan, and you still have to clean the house for the meeting. Describe your feelings. What would you do?
- J. Your son has spina bifida and uses a wheelchair. Last night you had a vivid dream that has stayed on your mind all day. You dreamt of your son climbing up the slide on the neighborhood playground and running off to greet a friend when he reached the bottom. Describe your feelings.
- K. Your child is shy and has worked hard in speech therapy for the past six months. She loves the praise she receives whenever she tries to talk with family members and the therapist. Today she attempted to talk to some older children on the playground. These children imitated her misunderstood words and ran off to play elsewhere. Describe your feelings. What would you do?
- L. Your child has been receiving physical therapy for the past 18 months. He has just taken his first independent steps. Describe your feelings. With whom would you most like to share this achievement?
- M. You have just completed a 12-hour work shift. The house is a mess. You have to make lunch for your eight-year-old. There are no clean clothes for school tomorrow, and your child with sensory integration issues is having a tantrum because you tried to feed him mashed potatoes instead of his favorite macaroni. Describe your feelings.
- N. Your seven-month-old baby is not rolling over like your friend's baby who is younger. Your mother has been telling you something is wrong. You

bring this to the attention of your pediatrician, but she is unconcerned. How do you feel? What would you do?

- O. You are late for work again this week, and your child with pervasive developmental disorder (PDD) refuses to wear the last available clean shirt because it's "itchy." Describe your feelings. How would you resolve this?
- P. Your child is in the hospital for another shunt revision. You are worried about meeting the needs of the siblings left at home. Someone from your church calls to tell you they will take the siblings to school and prepare meals for your family. Describe how you feel.
- Q. Your child's services will soon be changing as he is approaching three years of age. Your service coordinator has worked with you to develop a plan to prepare your child, but now the local education agency informs you that services may not be available during the summer. Describe your feelings. What would you do?
- R. The community child care center that your oldest child attended, calls to let you know they would welcome your daughter, who has cerebral palsy into their program. Describe how you feel.
- S. At your first team meeting, after the introductions are made, the evaluator tells you that your 15-month-old son demonstrates skills that are typical for a child at the six-month level in cognition. Describe your feelings.
- T. A little girl in your son's child care center invites your son, who has Down syndrome, to her birthday party. Describe your feelings.
- U. Your early intervention service coordinator called just to ask how you were doing. Describe your feelings.
- V. You just moved to this state and will be starting a new job on Monday. Your service coordinator is helping you locate child care facilities in your area. Describe your feelings.
- W. You can't afford the hearing aids that have been recommended for your daughter. Your service coordinator explains how funding for this may be obtained. Describe your feelings.
- X. Your child has just been diagnosed with a rare chromosomal anomaly. Even his physician has only seen one other child with this disorder, and that was years ago. Your service coordinator connects you with a national organization for this disorder. They have a parent support component,

and you are able to locate another parent with a child who has this disorder. Describe your feelings.

- Y. You serve on the board for a local therapeutic horseback riding program, are the president of your oldest child's parent-teacher association, volunteer for the autism support group in your area, and write for the association's newsletter. Your service coordinator just called to ask if you would serve as the parent representative on the local interagency coordinating council (LICC). Describe your feelings. What would you do?
- Z. Your daughter has multiple challenges. You've been struggling to find a way to bathe her without hurting your back. Your daughter's occupational therapist has recommended a bath chair, and your service coordinator has found an appropriate funding source. Describe how you feel.

Does this exercise make you feel uncomfortable? Did it seem like the problems would never end? Families of children with special needs often feel lonely, left out, overextended, frustrated, angry, embarrassed, isolated, unsure, embarrassed, and overwhelmed. The next time you, as a service coordinator, wonder why a family is not responding, think of this exercise. The supportive role of the service coordinator can make a real difference in the lives of families.

ABC's of Special Needs Worksheet

Write your response to scenario #2.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Describe scenario #3.

Write your response to scenario #3.

[illegible]



Life Stories from the Journey

Worksheet

1. What did you find the most surprising in the family life stories?

2. From listening to the family life stories, list one example where family-centered practices were not followed.

3. Describe how the above situation could have been improved from the family's point of view.

4. Describe how the attitude of the service coordinator influences a family's ability to receive supports and services in a family-centered manner.

5. List one thing you learned from the family life stories.

Name of participant _____ 10.3a



Family Interview Questions

1. Tell us about your child, and how you came to know your child had special needs.
2. What was the first step that was taken to address your child's needs?
3. Describe your feelings during this time of searching for solutions.
4. Describe your experience in sharing what you learned about your child with family members.
5. Was there a key person who was helpful when you were learning about your child's special needs? If so, describe how they were helpful.
6. Families of children with special needs participate in many IFSP and IEP meetings. Describe your experiences, both positive and negative, in meeting your child's educational needs.
7. Describe your experience in meeting your child's social needs.
8. Describe your experience in meeting your child's medical needs.
9. Have your child's treatment, therapy, or equipment needs been limited by finances or insurance coverage?
10. Describe the impact your child's special needs have had on the family, including siblings, grandparents, etc.
11. If you were a service coordinator, what would you keep in mind in working with families?
12. What is the best and worst advice you ever received?